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ABSTRACT

This compilation brings together various conference papers and a working group report on the topic of residential services for people with deaf-blindness and other profound disabilities. The title paper by Lyle T. Romer describes three measures for evaluating residential programs: capacity, progress, and lifestyle. Valued outcomes of a residential services program are defined and measured, focusing on the Valued Outcomes Information System as a measure of lifestyle quality. A response by George H.S. Singer, titled "A Systems Approach to Quality Residential Services for Those Who Are Profoundly Handicapped with Deafness and Blindness," discusses policies, community services, and organizational characteristics required to create desirable homes. A response by Stephen S. Barrett titled "Trends and Issues in Developing Community Living Programs for Young Adults Who Are Deaf-Blind and Profoundly Handicapped" outlines a continuum of community living alternatives; examines the issue of categorical versus integrated settings; and considers the role of parents in planning, funding, and implementation of programs. The report of the Working Group on Community-based Housing Options describes program characteristics, issues, and recommendations for policymakers regarding community residential options for young adults who are deaf-blind. (JDD)

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SECTION I. COMMUNITY-BASED RESIDENTIAL OPTIONS

Community-based Residential Options for Persons with Severe/Multiple Disabilities: Impact of Services on Peoples' Lifestyles

Lyle T. Romer

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Introduction

Over the past 10 years residential services for people with disabilities have undergone a notable shift in direction. Approximately 6,000 persons per year have moved from large, publicly operated residential facilities to programs providing residential services in community settings (Hill, Lakin, & Bruininks, 1984). These authors also report that residential programs are becoming smaller, with a mean of 25 residents in 1978 and 18 in 1982. These changes in size reflect decreases in the numbers of people living in public facilities serving 16 or more residents, only minimal growth in private facilities serving 16 or more residents and, most notably, an increase in the number of people served in privately operated programs for less than 16 residents. Despite these changes in location of services and size of programs, 64.5% of those receiving services still reside in facilities serving 16 or more persons, with 58.4% living in programs serving 64 or more residents (Hauber, Bruininks, Hill, Lakin, Scheerenberger, & White, 1984). If these trends toward smaller numbers and movement to community settings continue, then community programs will be offering services to increasing numbers of people with severe and profound disabilities, since these people constitute the majority of those still residing in the large public and private facilities serving 16 or more individuals (Hauber et al., 1984).

The principle of normalization (Bank-Mikkelson, 1969; Nirje, 1969; Wolfensberger, 1972) has provided the major philosophical orientation for the deinstitutionalization movement in this country. Normalization states that citizens with handicaps should have access to the same rights and benefits that are available to all other members of society. In addition to equal rights, normalization supports the use of ". . . means which are as culturally normative as possible, in order to establish, enable, or support behaviors, appearances and interpretations which are as culturally normative as possible . . ." (Wolfensberger, 1980, p. 80). Deinstitutionalization became a direct outgrowth of normalization in that it was not considered normative to live in ". . . a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life . . ." (Goffman, 1961, p. xiii).

The deinstitutionalization movement has addressed itself to the means for achieving normalization but has nothing to tell us about the influence of this movement upon the quality of life experienced by the persons who have moved. Research programs designed to investigate the success of deinstitutionalization will have little to offer to the future development of residential support programs unless the features of a successful program are identified. Success can be specified in terms of the features of a residential program, changes in the characteristics of the people who receive services from programs, or the ways in which service recipients lead their lives. We have to accept the responsibility of specifying what outcomes we expect from our residential programs before we are capable of determining the most effective means for achieving these intended outcomes. In order to specify where we want to go, we must be able to identify what is valued for people with disabilities. Certainly, no one has the right to specify what is valued in another person's life in any specific sense, but we should be willing and able to identify the framework we will employ for individuals and/or their advocates to make these determinations. Several frameworks for specifying the features of successful programs have been developed and employed. The next section of this paper critically examines these frameworks.

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Evaluating Residential Programs

Bellamy, Newton, and Lebaron (1985) have proposed a structure for examining the various ways to evaluate the impact of residential programs on the lives of their service recipients. They describe three categories of measures of quality in program evaluation: capacity, progress, and lifestyle. While there may be some degree of overlap among these, they are useful for both examining the current state of program evaluation and also for designing a comprehensive evaluation plan.

Capacity as a Measure of Quality

Evaluation based on capacity looks at a program's physical attributes and procedures that are assumed to bring about normalized outcomes for people served. Items such as the size and location of a home are assessed, as well as the presence of appropriate procedures for resident admissions, safety plans, number and classifications of staff, and so on. If one were to assess physical integration through a capacity measurement approach, one would evaluate whether the home were located in or near population centers and near community resources. ACMRDD, CARF, and ICF/MR regulations are probably the most widely used measures of a program's capacity for providing quality services. Several other capacity measures have appeared in the recent literature: the Multidimensional Environmental Assessment Procedure (Moos & Lemke, 1979), PASS 3 (Wolfensberger & Glenn, 1975), PASSING (Wolfensberger & Thomas, 1983), Resident Management Practices Scale (King, Raynes, & Tiard, 1971), Index of the Physical Environment (Pratt, Luszcz, & Brown, 1980), and MacEachron's (1983) physical environment index adapted from Morris (1969) and Gunzburg and Gunzburg (1973). All of these capacity measures enjoy one and the same advantage: They are easily administered. They also provide some information that may not be assessed in ongoing measures of quality and resident lifestyles, such as the comfort and attractiveness of the home, staff practices toward residents, and the presence of adequate safety features to minimize the likelihood of atrocities occurring. The major disadvantage of relying solely on capacity measures for evaluation is that they never directly measure the resident's quality of life. It is quite possible to have a program located in the heart of a suburban neighborhood, but, in actuality, residents may only leave the grounds of the home each morning by a special transportation system to be taken to a segregated school or sheltered workshop, to return home in the late afternoon by the same transportation system. Staff, instead of residents, may do all of the functions that would normally require physical integration such as grocery shopping, banking, dealing with social service agencies, and so on. Some programs, most notably ICF/MRs, may even provide services in the home that are usually acquired in the community, such as medical examinations by the program's consulting physician, haircuts, and exercise activities in the home's therapy pool instead of at the pool at the YMCA. Lastly, the capacity measures will not necessarily ensure the same level of opportunity for people with severe and profound disabilities as they mignt for people with milder disabilities. While it may be sufficient for people with mild disabilities to be close enough to community services to be able to use them, residents with more severe disabilities will often need more support.

Progress as a Measure of Quality

Evaluation according to progress assesses the extent to which residents are acquiring the skills perceived to be necessary for participation in activities whose patterns approximate those of the general population. This approach to program evaluation assumes that the acquisition of certain skills will afford a service recipient access to the benefits associated with a high-quality lifestyle. Measures of progress are also future oriented in their reliance on skill acquisition as an indication of the future lifestyle of the service recipient. This orientation toward the future is also apparent

in the evaluation of program success based on movement through a defined continuum of residential services (Schalock, Harper, & Genug, 1981). While the results of skill acquisition provide a measure of quality (as far as skills are concerned) they still only indirectly measure the quality of life enjoyed by a service recipient. Current progress measures in common use include the Adaptive Behavior Scales (Nihira, Foster, Shellhass, & Lealand, 1974); the Progress Assessment Chart (Gunzburg, 1977); and the Behavior Development Survey (University of California, Los Angeles, 1979). Some states have developed their own measurement systems directed toward evaluation of resident progress, such as the Client Evaluation Record (CER) (State of Oregon, 1979) and the Developmental Disabilities Information System in New York (Janicki & Jacobson, 1979). Progress measures of program quality offer certain advantages over the capacity measures. Measuring resident skill acquisition is more responsive to programmatic interventions. If a resident is not acquiring new skills, staff may design a new intervention specifically for that resident, whereas it would be difficult to redesign some of the capacity measures for the benefit of one resident, for example, to change the location of the home. Progress measures also offer the advantage of focusing on independence which is one of the valued outcomes for residents. Increasing resident skills is consistent with the developmental programming model. Increasing independence, however, is an uncertain indicator of program quality because once again, the measurement of skill levels is an indirect index of impact on the lifestyle of residents. The acquisition of skills in instructional environments is no guarantee that these same skills will be synthesized into a functional activity by the resident (Brown, Nietupski, & Hamre-Nietupski, 1976). Furthermore, some of these skills prove to be unnecessary, or impossible to acquire, for some residents. In such cases adapted performance strategies provide alternate behavior forms for residents to utilize to achieve the same functional outcome of an activity (Baumgart, Brown, Pumpian, Nisbeth, Ford, Sweet, Messina, & Schroeder, 1982; Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenewald, 1979; and Whilet, 1980). This over-emphasis on skill acquisition actually presents a disincentive to programs serving residents with more severe or profound disabilities. Programs serving these individuals may not be able to demonstrate progress in either skill acquisition or movement to other levels in the residential continuum. Programs serving more severely disabled residents require alternative ways to measure lifestyles--one that does not assume that achievement of complete independence is the only measure of a high quality lifestyle. Achievement of independence may not even be a realistic goal for many persons with more severe and profound disabilities.

Lifestyle as a Measure of Quality

Some capacity measures are important for preventing atrocities and for measuring some program characteristics on a less frequent basis. Progress measures focus on outcomes to residents. However, neither are adequate indicators of quality in residential services or in the positive impact on lifestyles. These shortcomings are due to the indirect nature of the measures; that is, they never directly examine the lifestyles of the service recipients. In contrast, use of lifestyle measures reduces the level of inference that is built into the capacity and progress measures. A certain level of faith is required to infer that, because a program's environment and procedures demonstrate some capacity for integration, or that a program's residents are gaining new skills, that these residents are therefore experiencing a high-quality lifestyle. If it is agreed that physical integration (engaging in activities outside the home) is a valued feature of a high quality lifestyle, then direct measurement of the number of times a resident engages in such activities is warranted. Capacity measures will reveal, to some degree, the extent to which this may be possible. Progress measures will reveal if a resident knows how to ride buses or cross streets safely, but only the direct examination of the resident's daily activity pattern will demonstrate whether physical integration is being achieved. This measurement strategy also diminishes the single focus on skill acquisition as a

measure of quality. Since physical integration provides the level of measurement, more flexibility is afforded to the program and resident as to how this is achieved. Adapted performance strategies or staff support to engage in activities in the community can supplement skill training for residents with more severe disabilities. Since the lifestyle measures focus on current lifestyle, they are appropriate for persons with severe or profound disabilities for whom complete independence is not a current or realistic goal.

Access to a high-quality lifestyle should not be contingent on movement to some higher level of the service continuum or the acquisition of prerequisite skills. The quality of a person's lifestyle is too important to be bargained away on the assumption that it will be better in the future, especially when the future is uncertain or distant. Lifestyle measures afford the opportunity for service consumers, providers, and planners to define not only the features of a normalizing service, but also the normalizing outcomes that service consumers would achieve. The utilization of lifestyle measures in residential programs has been limited to infrequent but exciting possibilities for improving the lifestyles of people with disabilities. Edgerton (1975), and Edgerton & Bercovici (1976) employed a lifestyle measure that might be referred to as "life sharing." In this approach the investigator actually shares in the residential experiences of people with disabilities and reports the results of observations, interviews, and conversations in order to form a picture of the individual's lifestyle. Other authors have collected information on service recipients' lifestyles through structured interviews or self-reports of activity patterns and the nature and extent of community contacts (Dalgleish, 1983; O'Neill, Brown, Gordon, Schonhorn, & Greer, 1981; and Sowers, 1982). Finally, direct observation of people in their residential service settings has been employed by several investigators (Butler & Bjannes, 1978; Landesman-Dwyer, Sackett, & Kleiman, 1980; Landesman-Dwyer, Stein, & Sackett, 1978; and Singer, Close, Irvin, Gersten, & Sailor, 1984). In each case except Singer et al. (1984), discrete units of behavior formed the basis of the coding systems. Singer et al. adapted the Weekly Activity Interview (Sowers, 1982) to directly record the activities engaged in by group home residents. If we agree that measurement of lifestyles may provide an appropriate framework for evaluating the impact of residential programs on the lives of people with disabilities, then the identification of the features of a high-quality lifestyle becomes our next task.

Defining Valued Outcomes of Residential Services

Program design should never proceed without first identifying the values that drive the organization's systems. If an organization's values are to provide the world with an inexpensive supply of food, then perhaps the Nestle Company has done an admirable job. If, however, the values were to provide a source of nutritionally sound food, then Nestle's may have to retool to be in line with these values. Likewise a residential program that values protection of people with disabilities from the dangers of living in our society would be expected to go about its business very differently from a program that values integration and participation in the activities available to the general citizenry. Figure 1 depicts the relationship of values to the issues of program design.

Decision making that is related to a program's values will significantly influence all aspects of the program, such as (1) the design of the technology to achieve these values; (2) the organizational structure that will best facilitate the valued accomplishments; and (3) the information system employed to provide feedback on the program's success. These decisions, to be truly effective, should always be made in reference to what is valued by the organization. Following the earlier example, the program that values protecting its residents from the dangers of society will organize itself to maximize close supervision of residents by regimenting daily routines and providing all necessary services in a closed and isolated environment. The technology will maximize the control of resident access to activities and people, and the information system will focus on the reporting of incidents that have endangered residents. In contrast the program that values integration and participation will organize itself to be

Figure 1.
Relationship of values to program design.

in close proximity to community resources and other members of the community. It will employ a technology that teaches people to become more competent in accessing their community and developing social networks, and its information system will provide feedback regarding the extent to which service recipients are participating in community activities.

The determination of residential service values proceeds by examining the valued outcomes desired by three groups of people: the service consumers, the parents/advocates of people with disabilities, and the service providers. Several authors have emphasized the need to address quality of life in program evaluations (Bruininks & Lakin, 1985; Emerson, 1985; and Heal, Sigleman, & Switzky, 1978). Quality of life has been defined in terms of physical integration in the community (Zigler & Balla, 1977), and social integration (Balla & Klein, 1981; Heal et al., 1978; and Janicki, 1981). Willer and Intagliata (1984) stress the need for quality of life measures in addition to the more traditional focus on developing independent living skills. Zigler and Balla (1977) further state that "any comprehensive program of research must take into account not only the behavioral functioning of residents but the quality of life they experience [and] the extent to which they maintain contact with the community . . ." (p. 10). Input from parents/advocates, service consumers and residential service providers was gathered through the efforts of the Neighborhood Living Project, a joint research and development effort of the University of Oregon's Specialized Training Program and the State of Washington's Division of Developmental Disabilities (Newton, Boles, Romer, Bellamy, & Horner, 1985). This information was used in the design of the Neighborhood Living Model which will be described further in the next section of this paper. Additional information on the outcomes that would be valued in residential programs was available from the State of Washington's Division of Developmental Disabilities Residential Services Outcomes Task Force which was also made up of parents of people with disabilities and residential service consumers and providers. The Task Force was charged with the task of developing guidelines for the measurement of those outcomes that were to be valued in residential programs which contracted to provide such services in the State of Washington. This process resulted in the inclusion of five values in the Neighborhood Living Model: physical integration, social integration, variety of activities, independence in performing activities, and security. Table 1 provides the operational definitions of these valued outcomes. Other outcomes valued in residential services were identified but are not currently included in any measurement system. These values include choice in one's lifestyle and health. Provisions are included in the Neighborhood Living Model to address these values, but they are still capacity or progress measures. Plans are being developed to define them as outcomes and build measures for these values.

Table 1.
Lifestyle Outcome Measures.

Outcome	Measure
1. Physical Integration	The number of activities performed outside the property boundary of the home (or communal areas of an apartment).
2. Social Integration	The number of activities performed with individuals who are not (a) staff members, (b) persons paid to work with individuals with developmental disabilities, or (c) other residents. Separate brief contacts, extended contacts, contacts with significant others.
3. Variety	The number of different categories of activities performed within a given time period (week, month, etc.).
4. Independence	The number of valued activities performed without staff assistance.
5. Security	The number of months of continuous support without forced movement to a restrictive setting.

Measuring Valued Outcomes in Residential Services

The remainer of this paper describes a measurement system designed to assess the lifestyles of persons with moderate, severe or profound disabilities who receive 24-hour residential support services. This measurement system was developed as part of the Neighborhood Living Model.

The Neighborhood Living Model is a comprehensive set of systems for integrating eight or fewer people with severe disabilities into their local communities. The model was developed to have a meaningful impact on the lifestyles of residents. There are four important components to the model: (1) the values that have been used to guide development of model procedures, (2) an internal data system that measures the lifestyles of residents, (3) a training and intervention technology that helps residents to gain and maintain adaptive behavior, and (4) an organizational structure that promotes program longevity and effectiveness. This internal data system forms one component of a comprehensive approach to program evaluation. Some elements of program quality would be difficult to measure on a repeated basis within a residential service setting. Elements such as program size and location, respect for residents, and privacy should still be assessed through periodic evaluation from persons or agencies external to the service program setting. Some of the previously discussed evaluation strategies can be employed for this purpose. The Valued Outcomes Information System (VOIS), which forms the internal data system, addresses itself to examining those indicators that were determined to index the quality of life experienced by service recipients.

Development of the internal data system was guided by six characteristics felt to be fundamental for any system to be useful to consumers, service providers and parents/advocates. These characteristics included the following:

1. Data should be tied to valued events in a service recipient's daily life.
2. Data system should be simple to use, that is take no more than a two-day inservice to learn.
3. Data should not require more than 5% of total staff time for collection and summarization.

4. Data should be valid and reliable.
5. Data should be used for decision making.
6. Program staff should not require continued external support to operate the system.

The requirement that data be tied to valued events was addressed by the decision to use activities as the unit of organization for the data collection system. Wilcox and Bellamy (1982) presented the rationale for using activities as a unit of analysis, as opposed to skills or other discrete units of behavior. They defined activities as age appropriate, functional units of behavior that create natural consequences in a person's life. Using a public telephone, going to the bank, and purchasing groceries are activities; identifying numbers, signing one's name and counting change are skills. An activity is made up of an integrated set of skills that result in a functional outcome that may be maintained by the consequences of the activity. In order to categorize activities into a system that would allow for ease in tracking daily patterns of valued events, an activity catalog was developed for use in residential settings (Bellamy & Wilcox, in press). This catalog consists of some 170 activities that are available in the local communities where residential services are provided. Each local program has the option of adding activities to the catalog that are unique to the community. The catalog consists of two domains--Personal Management and Leisure. Each of these domains is further divided into categories such as media, exercise, games, crafts and hobbies, and events, in the Leisure domain; and self, food, space and belongings, and personal business in the Personal Management domain. Each activitiy has a unique 3-digit code. For example, going to a movie is 1.4.3, which indicates that it is 1, in the Leisure domain; 4, in the category of events; and 3, attending a movie. While this may sound complicated at first, in fact, staff of residential programs using this system quickly become familiar with the most commonly encountered activities.

Once activities were defined as the unit of organization, rules were developed regarding which activities should be recorded. Any activity that is physically integrated, that is, occurs outside the property boundaries of the home, and any activity that is socially integrated, that is, is accompanied by someone other than staff or other residents, is considered to be a valued lifestyle indicator and is therefore recorded for all residents. Other activities that are of unique interest or importance to a specific resident are targeted as objectives in the IHP process and recorded whenever they occur. These activities are selected by the resident, parents/advocates and staff for either training (increasing the level of independence) or as participation activities (no current objective for training but some specified level of performance opportunity is guaranteed in the IHP process). Participation activities are those that are important to the resident's lifestyle but are not targeted for an increased level of independence. Staff provide whatever scheduling and support is necessary to achieve the specified level of performance opportunities.

Data are gathered through the use of small-size Post-It notes that are imprinted with a template to record the following: the resident's name, who accompanied the resident, what the activity was, when it occurred, where it occurred (home or community), whether it contained social integration, and whether training occurrred (whether task analysis data were collected). These tags are then summarized on a weekly basis by staff. Lifestyle graphs are then constructed showing the proportion of activities that were socially integrated, physically integrated and contained training. Figure 2 is a representation of a lifestyle graph for one resident.

The top line of the lifestyle graph labeled social integration indicates the total number of valued activities performed by the resident each week. The total includes all activities that were either physically integrated, socially integrated or were listed as an objective on the resident's IHP. The area labled As on the graph, between the top line and the line below it, are all the activities that did not involve social integration for this resident. The areas labeled P, Ap, and So together represent all the activities that involved social integration for this resident. The P area represents the activities

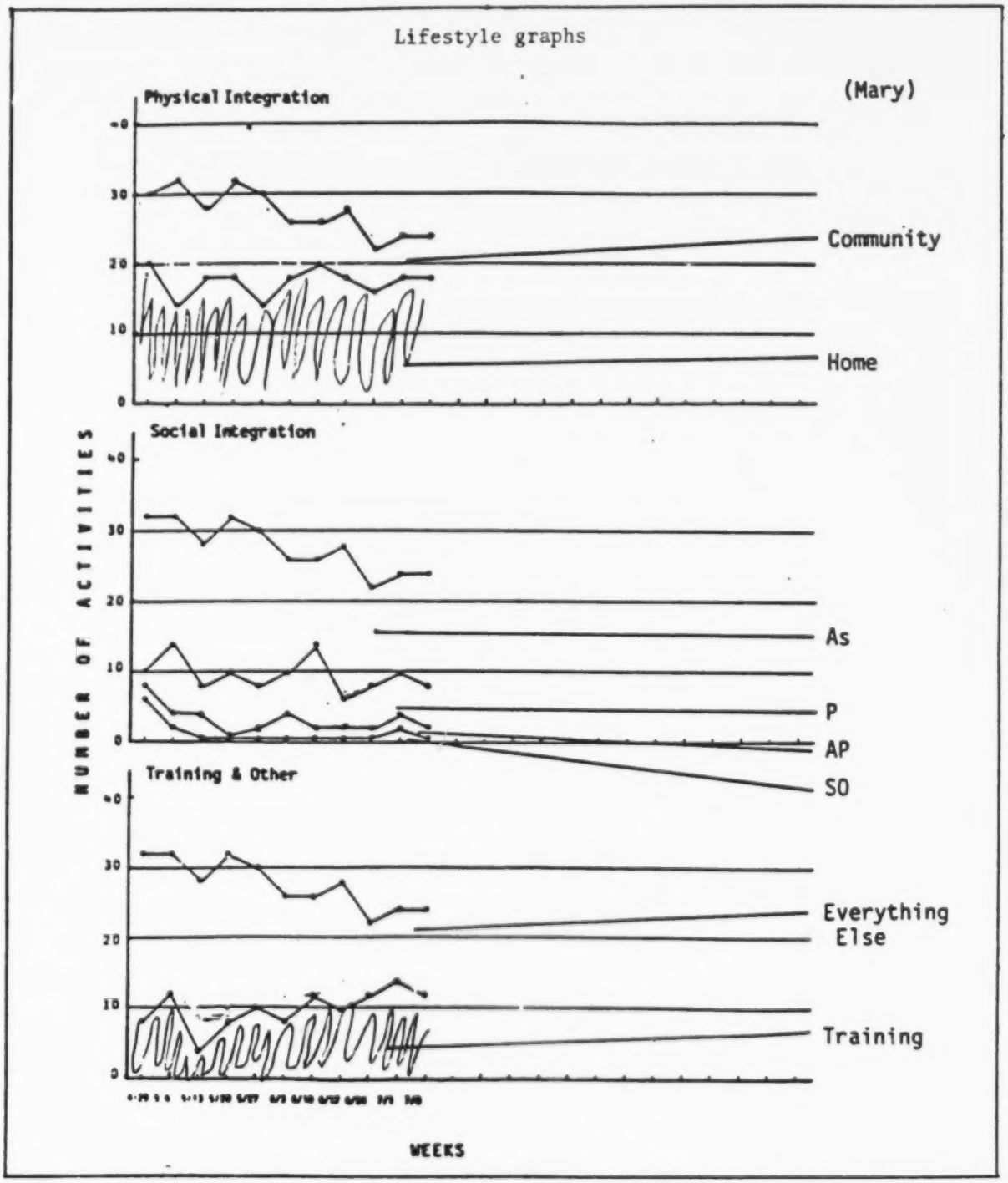

Figure 2.
Resident (Mary) lifestyle graphs.

that contained brief social contact, such as a short two-way reciprocal interaction. The Ap area represents all activities that contained extended social integration, such as performance of an entire activity with someone other than staff or other residents. The So portion of the graph represents the activities that the resident engaged in with significant others, such as members of his/her family or persons who were listed on the IHP as being significant others in the resident's life. The physical integration lifestyle graph shows the proportion of valued activities that the resident engaged in in the home and in the community. Last, the training graph depicts the number of activities engaged in by the resident that included training, that is, task analysis data were gathered by staff on the resident's performance and the activity was listed as a training objective on the IHP.

The process of filling out tags, summarizing data and constructing the lifestyle graphs took about 2.5% to 3.5% of total staff time as reported by the nine residential programs currently using the VOIS.

Once data are summarized into information regarding the residents' lifestyles, they are incorporated into decision or feedback loops. The essential features of a feedback loop are (1) a planning stage in which standards for performance are established; (2) a performing stage in which the service organization fulfulls its responsibilities; (3) measuring, which includes summarizing the data; and (4) comparing the measured outcomes with the standards established in the planning stage. Once the loop is completed, or closed, the planning stage is entered again and the loop is employed to provide continuing feedback on a predetermined schedule. Figure 3 is a schematic rendition of a basic decision loop.

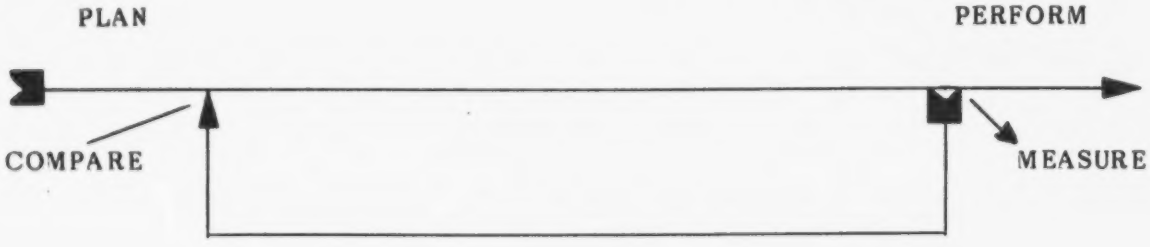

Figure 3.
Feedback loop.

The VOIS employs three distinct decision loops: consumer/advocate, staff, and board of directors. Each loop has its own unique features. The consumer loop runs on a six-month cycle that coincides with each IHP development meeting. This loop contains plans for the lifestyle measures of the resident on a six-month basis, the summary for the six-month period, and comparisons to the standards established in the planning stage of the previous IHP meeting. The board of directors decision loop closes on a monthly basis. The program's director provides the board with monthly summaries of information related to resident lifestyles. The staff decision loop, logically, closes more frequently on a weekly basis. This permits timely monitoring of the progress toward IHP objectives and informed decision making in the area of lifestyle outcomes. These loops support answers to questions regarding the extent of physical and social integration in a resident's lifestyle and the degree to which training occurred. Outcome measures of variety of activities and independence are computed using the activity catalog and incorporated into the decision loops of the consumer and the board of directors. These measures assess variety by examining the distribution of activities across categories and independence by asking staff to rate the level of support residents have received for engaging in the activities contained in the catalog.

The VOIS is currently in use in eight residential service programs in the state of Washington and in one program in Alaska. These programs include five Intensive Tenant Support programs providing services, in their apartments, to individuals with moderate to severe disabilities, three group homes, and an adult family (foster) home. A total of 58 residents are served through these programs, all of whom have moderate or severe disabilities.

Conclusions

The VOIS is one way to examine the lifestyles of persons with disabilities for the purposes of evaluating and designing residential services. This system will be expanded over time to include other important features of quality in lifestyles. Distinct advantages in using the VOIS over other measures of quality in residential programs include the removal of the high level of inference regarding actual lifestyles, which is inherent in the capacity and progress measures; the opportunity for service consumers and their parents/advocates to make better informed choices about where a person may choose to live; and the fact that while the VOIS defines the framework for lifestyle measurement it does not dictate what a lifestyle should be for individuals. This last advantage in the VOIS allows for informed lifestyle planning involving the service consumer and the significant others in his/her life (O'Brien, in press). However, the most important feature of the VOIS is that it defines what we value as outcomes of our residential service programs. We currently debate the need for more staff in residential programs, technical assistance to programs, the effect of size in our programs, the level of skills needed by staff and how to best develop these skills. What we lack is a viable method to determine the impact these various interventions have on the quality of residential service. The VOIS, and other measures of lifestyle that can be employed at the service delivery level, allow us to assess this impact where it is most critical, on the lifestyles of the people receiving services. No amount of research will validate normalization and deinstitutionalization as valued goals, nor will research provide us with the answers to what should be the outcomes of quality residential services. Our ideals and our goals are value decisions and are not subject to validation through the scientific method. Research is essential to develop strategies and tactics for improving the quality of our services. But first, we must know what quality is.

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In Response to Lyle T. Romer

A Systems Approach to Quality Residential Services for Those Who Are Profoundly Handicapped with Deafness and Blindness

George H. S. Singer

Introduction

This conference has been called in order to develop recommendations based upon the needs of students with handicaps of deafness and blindness who are leaving school services and entering the adult service system. Our emphasis is on transition to adult services of those individuals who experience deaf-blindness and other profound, multiple handicapping conditions. This session is concerned with residential alternatives. In this context I would like to comment briefly on Lyle Romer's excellent paper and then discuss some of the implications of serving individuals who exhibit severe aberrant behavior in community living arrangements. Because our context is broad, covering service needs and policy implications, this paper will discuss several issues. I will first talk about what we hope to achieve for young adults who are severely handicapped and then discuss some of the policies, community services, and organizational characteristics that are required in order to create desirable homes. I will talk about several layers of the service system, starting with the daily schedule and social interactions of a person who experiences deaf-blindness. I will then move on to discuss the organization that provides home-living services, and then on to some of the essential community services that are required to create successful living arrangements. And finally, I will talk about some of the federal and state policies that have a decisive impact on the quality of daily life of individuals who experience severely handicapping conditions.

The Person Who Is Profoundly/Multiply Handicapped with Deaf-Blindness: A Description

The population of those who are deaf-blind, like the larger population of severely handicapped individuals, is extremely heterogeneous. This discussion will be focusing on individuals who experience deafness and blindness in addition to severe to profound mental retardation. A large percentage of these young people experience additional handicapping conditions including cerebral palsy, epilepsy, and other chronic medical conditions. Many of these individuals will leave school without having learned a symbolic communication system; those who have learned a symbolic system will have a very limited linguistic repertoire. A significant number of these young people will exhibit severe aberrant behaviors, one of the primary causes of first placements and returns to institutions and, ostensibly, one of the main obstacles to placing individuals in the community (Hill, Lakin, & Bruinincks, 1984). The problem behaviors that are associated with institutionalization are self-injurious behavior, assaultive behavior, severe noncompliance, and destruction of property (Scheerenberger, 1981). Thus a discussion of community living for these individuals needs to take into account their need for several services including behavioral and medical treatment. The challenge is to meet these service needs in a homelike setting and in the context of a positive and culturally normal lifestyle.

Where Do They Live Now?

The majority of adults with profound/multiple handicaps of deaf-blindness are residing in institutions—public residential institutions and private nursing homes (Wolf, Delk, & Schein, 1982). Until recently, the institution has been the expected place of residence for these individuals. As a result, a majority of these adults reside in large public institutions, and many who live in the community reside in nursing homes and other mini-institutions (Wolf et al., 1982, Lakin, Hill, Hauber, & Bruininks, 1983). Needless to say, these are not homelike settings. The situation is different for the school-aged population. A recent survey of nine Rocky Mountain and Great Plains states showed that 38% of school-aged children who are deaf-blind were residing in institutions, 18% in residential schools, and the remaining 44% in community settings (Gates, 1985). Another recent study from New York state suggests a similar pattern. Although they did not provide specific information about children with deaf-blindness, Jacobson & Janicki (1985) did describe the living arrangements for children with multiple handicapping conditions and profound mental retardation. They found that twice as many frail/severely handicapped individuals, aged 21 or less, lived in the community as compared with the institution. The opposite was true of adults; only one in three lived in the community. It appears that many children are living in natural or foster homes and their parents expect that they can and will continue to live in community homes rather than institutions. But this outcome is by no means ensured. The prognosis for full community services for all persons regardless of the severity of their handicapping conditions is, at best, guarded.

On one hand, funding has continued to favor institutions and large facilities rather than homes (Fernald, 1986). Many people have been left in the large congregate-care institutions and many others have been transfered from one institution to a another in the community (Taylor, McCord, & Searl, 1981). And, sadly, some individuals have been placed in homes that are underfunded and insufficiently staffed, thereby creating "back wards" in the community (Bercovici, 1981). On the other hand, several states have aggressively created small group homes, apartment-living programs, and small scale ICF-MR home (Apolloni, 1980; Hitzing, 1980). Empirical evidence suggests that these community-living arrangements create new opportunities for growth in adaptive skills and for more normative, valued lifestyles (Conroy, Efthimious, & Lemanowiscz, 1982; Romer, 1986). Deinstitutionalization has proceeded at a rate of about 6,000 placements in the community each year with the recent movement made up mostly of individuals

with severe and profound mental retardation. At the same time there is a growing number of new community homes for individuals who have lived in the community their entire lives. As we serve more severely handicapped persons in larger numbers in the community, the issue of how to create homes for individuals with severe aberrant behaviors has become prominent.

On the positive side, there are now examples of excellent service models in several states. (Apolloni, Cappuccilli, & Cooke, 1980; Gage, Fredericks, Baldwin, Moore, & Grove, 1979; Singer, Close, Irvin, Gersten, & Sailor, 1984; Romer, 1986). However, the idea of community living in small homelike settings is relatively new and fragile, particularly for the group that concerns us here today. The community service system in most states has yet to develop homelike residences for medically frail individuals, people with severe aberrant behaviors, and people with multiple developmental special needs. If we want to create family-like homes for this group of people there are several service system components that must be in place. I believe that we can serve all individuals in positive family-like settings given adequate resources, sufficient community services, local leadership, and a clear understanding of our goal.

The Goal: A Positive Quality of Life

It is important to have a clear sense of the desired outcomes of the service system. In the most general sense, we want to provide a positive quality of life for the people we serve. The concept of quality of life as it is used in our field usually refers to one person's surmise of what life is like for someone who cannot speak for him - or herself. It would be a lot easier to agree on what makes a high quality service if we could simply ask our clients, "How's life?" For example, a recent study of semi-independent living programs for individuals with mild mental retardation relied extensively on interviews with the residents (Halpern, Close, & Walker, 1985). They spoke with considerable agreement about the sources of satisfaction and the troubles in their lives. With this kind of information, we might agree that a residential program that increased those sources of satisfaction and decreased the troublesome events would be improving a person's quality of life. The problem is more difficult though, when we have to make inferences about what life is like for a person who cannot easily revel how s/he feels and what s/he prefers.

Instead of asking, we have to resort to observing. But what to observe? Researchers such as Close (1977) have tended to emphasize skill development. Gaining new skills plausibly gives access to more independent participation in activities of daily living. Learning new skills has something to do with a good quality of life although we probably all know successful students who are unhappy and people who do not learn lots of new skills who say they are satisfied. And certainly too much emphasis on skill development might put people in a kind of pressure cooker instead of a home.

Social reformers such as Wolfensberger and Glenn (1975) have tended to emphasize the normalcy of the physical and social environment—the location of home, its proximity to stores and transportation, the amount of space and personal possessions for each resident in the home, the daily routine of the residents, the appropriateness of programming, and so on. These normalization dimensions probably have something to do with what most people associate with a good quality of life. However, we probably all know people who live in nice homes, have a normal rhythm of life, and still aren't happy.

Romer and his colleagues have added a more specific dimension of normalization by evaluating the frequency of valued activities and of social contacts. From this point of view, a service that delivers a high quality of life is one that creates a valued lifestyle made up of activities in integrated community settings.

So far, all of these ways of looking at quality of life direct attention to measurable outcomes of a social service and, on the face of it, seem to point to aspects of what many people would consider to be a good life. Quality of life is a concept with many

dimensions and we probably get closest to measuring it by looking at it from several different angles. In addition to looking at skill gains, normalization of the social and physical environment, and valued activities, I think that we need to look at the people whom we serve from two other points of view by asking two more questions: (a) How do the people who spend the most time with them treat them? and (b) Do they seem happy?

Remember, I am talking about people who need a lot of assistance to participate in normal activities of daily living. This means that someone—a friend, relative, foster parent, or group home employee is spending a lot of time in close contact with the individual. Research from the studies of depression and well-being with nonhandicapped people suggests that the quality of our close social contacts at work and at home has a lot to do with our morale (Cohen & Syme, 1984). The quality of caregiver/resident social interactions have been a major concern in institutions and poor quality community residences (Bogdan, Taylor, Grandpre, & Haynes, 1977; Bercovici, 1981). We are all familiar with reports of disrespect, disdain, and abuse. However, little attention has been paid to social interactions between caregivers and residents in good living environments. I would expect them to be characterized by two-way communication in which the individual who is deaf-blind not only receives but also initiates communication during dyadic interactions. Caregivers in high quality homes should be able to comprehend the expressive communications of their residents who are deaf-blind whether these are prelinguistic gestures, manual signs, or even states of alertness. Similary caregivers should communicate frequently about ongoing events--describing, commenting, and turn-taking. Many of these interactions would be characterized by good humor, gentlenes, and candor. And if an aberrant behavior is part of the communication, the staff person would respond with precision, correct technique, and an understanding of the function of the behavior in that specific context.

The second question I would ask about a resident of a community home is "Does s/he seem to be happy?" I am well aware of what a sloppy, slippery construct is at hand. If persons cannot tell you how they are feeling and if their nonverbal expressions are not part of the generally consensual nonverbal code of the culture, how do you know? Can we tell how severely handicapped people are feeling in different situations? Some efforts have been made to study social interaction in integrated school settings. These efforts should be extended to community living arrangements. We might need to further individualize this kind of assessment in order to include measures of affect. One approach would be to ask parents or caregivers who know a person very well to tell us when they think the individual is happy. A picture or videotaped record of some of these occasions could serve as a standard. A guardian, advocate, or program evaluator could observe a resident on several occasions and ask how often the deaf/blind individual looks like s/he did in the pictures that showed a happy state. Of course, other "harder" behavioral measures and indices such as rates of aberrant behavior, requests for continuation of an event, and attending to the environment would need to be considered.

An Example

I want to tell a brief story to indicate why the questions, "How do others treat the person?" and "How happy are they?" ought to be considered. I was recently asked to serve as an expert witness in efforts to mediate a dispute between a parent and a state department of education. The parent was alleging that her daughter's foster home and school placement were inappropriate. I was asked to evaluate both the educational and residential services that were being provided to Jill, a teenager who was handicapped with deafness and blindness. Jill has been totally blind as well as profoundly deaf since birth. According to her school records, she knew a few difficult-to-read manual signs and could understand a small number of signs made in her hand. Jill's mother felt that the foster home was highly inappropriate, even damaging. I asked that the foster parent keep a diary of the young woman's activities in the foster

home and in the community. I also used a normalization instrument to assess the home and social environment. The home was a new, large apartment across the street from the beach. The young woman had her own attractive room; she often went out with the family and played with the other teenager in the home. I watched her and the foster parent at home and at the beach. She behaved like many severely or profoundly mentally retarded people whom I know in that she was very passive. She never made efforts to communicate, did not initiate any activity without prompts, and seemed generally unaware of the environment. I observed her in her respite care program and classroom, where she behaved in much the same way.

Everybody was fed up with Jill's mother and I was beginning to wonder if maybe she had some unreasonable expectations. I met with the mother and we drove to a supermarket in her beat-up old car. All of a sudden, Jill came to life in the car. She started signing into her mother's hands, asking where we were going and what was for dinner. In the store, the guardian asked her to get some lettuce; the young woman who is totally blind felt the produce, found a head of lettuce, found her way back to the cart, put it in and signed "mom's lettuce." Next she asked for cashews by spelling the word. Back at her mother's home which was not nearly as well furnished, spacious, or clean as the foster parent's home, Jill helped with some parts of cooking dinner, asked to go play a game, came back and started a two-way exchange with her mother.

So, here were two contrasting environments. A foster home that seemed to provide "the good life." The location, the possessions, the activities all looked good. Her natural mother's home was more crowded, less attractive, and much further from the beach. But in the foster home, as well as the respite and classroom settings, Jill was largely ignored. People rarely tried to communicate to her, nor did they ever set up interactions that would prompt her to initiate communication. They expected her to be passive and uncommunicative. With her mother, she was a very different person. The interactions between the two women were very different in Jill's mother's home. And Jill looked happier, although her expressions were not conventional and took some time to learn.

Perhaps we are overlooking something. Clearly all of the things that were targeted in our Project S.A.I.L. homes such as skill development, a normalized schedule, activities in the community, and reductions in problem behavior were important (Singer, 1986). Clearly, the outcome measure that Lyle Romer has discussed is extremely important and represents a real contribution to our field. However, we should not shy away from more difficult to measure, but extremely important, indicators of quality of life.

The purpose of this discussion of quality of life indicators is to arrive at an understanding of what we want to create when we make living arrangements for severely handicapped individuals. I am assuming that we want to create living environments that do several things: increase skills, decrease aberrant behaviors, provide normal homelike surroundings, provide a schedule of valued activities, provide positive social interactions, and provide many occasions for happiness. I also assume that at different times these subgoals will be given different degrees of importance. For a person who injures himself, we may, for a time, have to give priority to decreasing the problem behavior over the schedule of community events. There may be times when skill development really matters when, for example, a new job opportunity comes along and a new skill would make placement possible. But each subgoal, at any one time, should be given some care and attention.

What do we need to do to create living environments where we can achieve these goals? And furthermore, what else do we need to do if a person exhibits serious aberrant behaviors?

Components of a Necessary Service System

In the service system, many things must happen on several different societal levels ranging from federal and state law to staff training practices. It is a complex system

with many interacting components. Ultimately, we measure the success of each service component by looking at an individual's quality of life. I have listed them in Table 1. To simplify, I have grouped the service components into domains.

Table 1.

State and National - Philosophy - Policy - Funding
Community Services - Case management - Guardianship and advocacy - Generic services
Organizational Variables - Philosophy - Governance - Leadership - Cohesiveness - Boundary management - Routine management - Personnel management - Social norms - Problem resolution - Planning and evaluation
Individual's Experience of Residential Service - Activities - Social interactions - I.P.P. goals - Attractiveness and accessibility of home

Individual's Experience

The first domain concerns the individual. There are several elements that come into view at this individual level on analysis such as a person's schedule of activities, social interactions, health, the presence of stressors, skills, individual program plan goals, and the attractiveness and accessibility of the environment.

Organizational Variables

The next level up in the system has to do with the immediate, most proximate determinants of success of the personal level variables. In group-home and apartment-living

programs, this level primarily consists of organizational variables. The characteristics of the service organization are primary determinants of the quality at the personal level. Just as the first level is made up of several elements that add up to individual program quality, so the second level consists of many variables that make up organizational effectiveness.

The daily life of a severely handicapped person is largely, but not entirely, determined by the quality of the organization that is providing a particular service. As much as any group of people in our society, severely handicapped people are at the mercy of the organizations that house, clothe, educate, employ, and entertain them. If the organization is ineffective, the person suffers. There are several ways to analyze an organization. For this discussion I will focus on a few variables that make up organizational effectiveness: philosopy, governance, leadership, cohesiveness, boundary management, routine management, social norms, personnel management, problem resolution, and planning and evaluation. There has been little discussion of organizational variables in human services for severely handicapped individuals. This is surprising. We know from a large body of research on public schools that there are effective and ineffective public schools and that effective ones have several common characteristics (Joyce, Hersh, & McKibbin, 1983). We need to have similar information about community services for severely handicapped people.

The following discussion is based upon our work in setting up group homes, school services, and parent support programs in various communities. Comparative research is sorely needed to verify these ideas. I will briefly discuss a few of these organizational variables; time will not permit a full discussion.

The people who govern and lead the organization share a set of organizing concepts about its purpose and values. Philosophies can be formal or informal, and the two may or may not be the same. In a cohesive organization everyone from the chairperson of the board of directors to the night worker in the group home knows the purpose of her work. Public verbal commitments are translated into behavior and outcomes. In the Project S.A.I.L. homes (Singer & Irvin, 1985) all staff members met weekly with the home director and, at times, with the chairperson of the board of directors; the meetings focused on the indicators of quality of life that the board had decided was important and the tactics or techniques that were effective in meeting goals.

Leadership is a critical variable in effective residential programs. We can create carefully designed service models that will presumably work anywhere. However, unless there is strong leadership even the best service model can fail to deliver a good quality of life. The organization's director needs to be able to work directly with residents as a major portion of his/her job and be able to model technically correct and friendly ways of interaction. He or she also needs to be skilled in other managerial roles; of special importance is staff training and personnel management. The organizational leadership also needs to manage effectively boundaries within the organization and between it and the external environment. For example, a common time in which programming breaks down in group homes is when shifts change; effective leaders establish ways for information to flow across the boundary formed by the shift schedule. Other boundaries include the home's relationship to the neighborhood and the agency's relationship to other community services. If well managed, these relationships bring benefits to the residents; if not, individuals and organizations are placed under stress.

Programmatic leadership and role modeling are made all the more important if residents are individuals who exhibit self-injurious behavior (SIB) or other severe aberrant behaviors. SIB is a complex and often difficult to treat problem. Examples of SIB include head banging, hitting other body parts against objects, biting, slapping, or hitting other body parts, ruminating, vomiting, and eye gouging. These kinds of behavior keep many individuals in highly restrictive environments, often living in various forms of restraints. Treatment is often difficult and people who must care for a self-injurious person experience real distress. When treating these kinds of problems, an effective

leader is able to model confidence, a strong sense of caring, and technical precision in working with the person who exhibits SIB.

If skilled and energetic leadership is as critical to successful community programming as I believe it is, then we need to be paying a good deal more attention to recruiting and training young leaders. We will have to make careers in the community service system more attractive and we will need to educate leaders about both administration and direct programming for individual residents.

Staff training matters greatly when serving young people who have complicated service needs, including severe problem behaviors. Ongoing training, along with coaching and monitoring, are the primary ways of maintaining effective and positive social interactions. Effective interactions mean that they teach skills or appropriate behavior. Positive interactions mean that they are friendly and respectful. In our staff training program (Singer, 1986) we have analyzed specific recurring forms of staff/resident interactions. We explain these interaction patterns and show videotapes of them to staff. This idea came from contact with the Achievement Place Model for troubled teenagers (Phillips & Fixen, 1975). In their model, they train houseparents in how to carry out a teaching interaction. These teaching interactions take some different forms when one party is nonverbal. But, in the same way, they can be analyzed and taught. One critical kind of social interaction involves learning to attend to the person's ways of making requests, protesting, and indicating (Riechle & Keogh, 1986). Videotapes of an individual resident's ways of communicating can be used to train staff to identify and respond to idiosyncratic forms of communication.

For the most part, staff of residential programs including foster parents are unskilled people who have had minimal formal training. They must become competent paraprofessionals. People with deaf-blindness and other handicapping conditions are often very complex in the ways that they give and receive communication, in their dietary and medical needs, and their need for structured environments to manage problem behavior. In order to learn and then use many caregiving skills, ongoing staff training needs to be a regular part of the organization. With the high rates of staff turnover in most residential programs there is a constant need for training new staff, for reminding old staff or their mission, and for continually upgrading skills. We believe that the person who has major responsibility for this training ought to be the one who hires and fires other personnel and who leads the organization. Some of the training can be delegated and perhaps some of it can be automated. But the director needs to be seen as an excellent example of how to be a friendly and effective assistant and educator with people who live in the home.

In order to address some of the problems of providing ongoing staff training, my colleagues and I at the Oregon Research Institute have been conducting research and development on the use of microcomputers connected to video recorders as a way to provide important parts of staff training for paraprofessionals. In one study we trained a paraprofessional to utilize four new teaching techniques with a deaf-blind child. Our data show that, in each case, a young paraprofessional was able to implement unfamiliar procedures by using computer-assisted video lessons (Singer, Sowers, & Irvin, in press). We believe that this new technology can be an important tool for staff development with paraprofessionals. Ongoing staff training is one of the most important ways to establish and keep a positive climate or culture within a community service organization. It helps to establish desirable social norms for staff behavior.

The social norms that prevail in an organization are the often unspoken standards that govern an employee's behavior. A difficult set of norms to establish is that a group home or foster home is both a home for the residents and place of work for the people who are paid to provide care. Work norms and domestic norms are usually very different. Well-managed residential programs are careful to make work expectations and standards very clear when they orient and train staff. Effective directors watch for ways that the program may drift away from the desired standards and act to

correct them. In addition to a work ethic, another important norm concerns behaviors that indicate respect, such as careful attention to a resident's communicative behavior and preferences. Once again the model of Achievement Place suggested to us that we could deliberately identify and train the kinds of behaviors implied by norms of respect and friendliness. In programs that serve individuals with severe problem behaviors there needs to be a norm that places a lot of value on precision, structure, and planning in interacting with a resident who exhibits aberrant behavior.

Another important organizational variable has to do with providing incentives and ways to elicit commitment from caregivers. Unfortunately, in many programs pay is low and the work is very demanding. As a result, employee turnover rates in community programs are often very high. Lakin reported annual rates of turnover averaging 80% in his survey of residential programs (1981). These problems can be compounded when the program serves individuals with severe problem behaviors. In studies of job stress for special educators and residential care providers, dealing with aberrant behaviors is usually one of th highest rated items since severe aberrant behaviors are highly aversive to most people. In working with dangerous behavior or even life-threatening behavior, staff often are working under conditions similar to those in a hospital emergency room. Staff have to be highly trained and they have to be able to control their own actions to behave in very precise and consistent ways. This is a tall order for someone who has had little formal training and is minimally paid. Effective organizations work hard to keep good people by offering recognition, a sense of group purpose, job advancement, and opportunities to make unique contributions to the program. Effective organizations can make efforts to reduce the effects of stress and to build nonmonetary job incentives but organizations also are strongly influenced by the broader context in which they exist.

Community Services

Community services are extremely important contributors to the quality of life of people in community living arrangements. I will briefly mention three of these: (a) the availability of generic services such as medical, dental, and dietician services; (b) the quality of case management services; and (c) personalized and effective guardianship and advocacy program. All are vital to deinstitutionalization. Placement in the community does not automatically ensure that needed, related services will be available. For example, recent reports express concern about the quality of medical and pharmacological monitoring of mentally retarded persons living in the community (Garrard, 1983). In working with individuals who exhibit aggression or self-injurious behavior, it is important to have medical consultation. Other service agencies such as the local police and the staff at the emergency room of the local hospital may have a role. Often these people have had no prior experience with severely handicapped individuals and our behavioral and educational approaches may be quite foreign to them.

A crucial player in obtaining these and other services can be a case manager. When case managers are knowledgeable about the people whom they serve, have manageable case loads, and work for well-managed organizations, they can be of tremendous benefit to individual service recipients (Magreb & Elder, 1980). A service that has been very impressive in our work with families of children who are deaf-blind and have other severe handicaps is a direction service. Direction services specialize in connecting people and their families who experience disabilities to generic services (Zeller, 1980). They use a case manager model. In our family support research at the Oregon Research Institute we have found direction service to be valued highly by parents and service providers alike (Singer & Irvin, 1985).

Personalized guardianship and advocacy services hold enormous potential for maintaining quality services. Someone who knows an individual resident well and who is a good friend to him or her over a long period of time needs to have whistle-blowing authority. We have to find ways to create and maintain strong personal commitments that endure for the individuals whom we serve. Many parents play this role. But

many persons who are deaf-blind have little family contact and no one lives forever. Some of the innovations developed by Apolloni and his colleagues (Apolloni & Cooke, 1984) hold great promise in this respect.

Another level of the service system consists of national and regional philosophies, policies, and funding. Briefly the philosophy of service provision has a powerful directive influence on all levels of the system. The concepts of normalization, equal access, and the developmental model shape much of our efforts. Our present philosophies are challenged and sometimes stretched to the limit in serving individuals who exhibit very severe problem behavior. Our desire to give access to integrated, normal, and friendly community settings can conflict with the need to provide treatment and safety for persons with severe handicaps and the people who work with them.

On the levels of philosophy and policy, there is now a heated debate about what kinds of behavioral treatments are acceptable in the community. TASH and the executive committee of ARC have come out with policies against the use of most kinds of aversive procedures. These policies have, in part, been in response to the apparent misuse and abuse of some behavior modification techniques. Often underfunded programs with untrained staff have relied on poorly designed and brutal procedures to control people with violent behavior in barren environments. TASH has contributed to a much needed movement to encourage the development of nonaversive treatment procedures. I believe however that we make an error if we ban outright all aversive procedures in community programs. In some cases, they may be the only effective alternative to nontreatment. These cases are few and far between. The great majority of individuals with severe problem behaviors, I believe, will respond to carefully structured positive environments and well-designed decelerative programs based upon detailed antecedent analysis and positive reinforcement of adaptive behaviors. However, for some individuals—notably, those who have long established histories of extreme aberrant behavior--these procedures alone may not work, and banning of some aversive alternatives may consititute a failure to provide needed treatment. In our work we have addressed this issue by establishing local human rights review committees and prima facie rules against the use of aversive or restrictive practices (Irvin & Singer, 1985). We believe that this policy alternative along with other necessary components of a comprehensive community service system can provide a vehicle for ensuring that individuals receive treatment while protecting them from inappropriate treatment. This issue deserves a much longer discussion but I believe it is an important example of how attempts to serve individuals with severe aberrant behaviors affects the top levels of the service system. They challenge us to examine and specify how our philosophical commitments apply in morally complex circumstances.

State and National

Another level of the system that ultimately shapes the quality of life of severely handicapped persons is that of federal and state legislation. Laws and regulations establish the parameters of many services. Recent efforts to reform Title XIX are familiar. Reform of Medicaid could help to dismantle the costly and failed system of institutions and to provide much needed fiscal support to community programming (Fernald, 1986). Although a shared mission and ideology can have an amazing power to mobilize people, money is also essential.

Federal funding for all programs for developmentally disabled persons represents less than 1% of the federal budget and less than two tenths of one percent of the GNP (Braddock, 1986). Even a brief glance at our current national defense budget might make us wonder about society's priorities. Those of us who believe in community services for everyone must be careful that their ideals are not used by legislators who are motivated primarily by the desire to cut costs. We should remember that many of the homeless, mentally ill people who now populate our streets are the victims of another deinstitutionalization movement.

Community residential services may be more efficient and cost effective than institutional care. However, at present, Title XIX waiver funding of community alternatives to the institution, in many cases, represents comparatively drastic cuts in community service funding compared to the institutional services that are being replaced.

Certainly we can save money--perhaps 10-20%--but we pay a terrible cost in quality of services when, for example, the going rate for institutional care is $120 a day and the highest possible reimbursement rate in the community is $60. These severe differentials in commitment of resources will not work when it comes to serving many of the most severely handicapped people who now make up the majority of the residual population in institutions.

While people who have needs for intensive behavioral interventions can be served effectively in the community, the services are relatively expensive. In order to employ people who can lead community organizations in the way I described earlier, we have to pay attractive salaries. In order to provide the high staff to resident ratios that are needed to deliver nonaversive behavior management programs, we need to be able to hire large numbers of staff. In order to provide working conditions that will attract and keep good direct service staff, we have to be able to provide a decent base rate of pay, vacations, benefits, and time for job development. Drastic reductions in funding as a person is placed in community services are not wise measures for individuals with needs for intensive behavioral services.

Individuals with extreme problem behaviors do pose a real challenge to the community service system. It has been met in many model programs. Donellan, LaVigna, Zambito, and Thvedt (1985) have reported on successful intensive in-home services for individuals with severe problem behaviors. McGee (1986) has reported on services in Nebraska that emphasize staff-intensive, highly concentrated behavioral interventions that use nonaversive procedures. My colleagues and I have reported on group home programs that have successfully served very challenging young people in California (Singer, Close, Irvin, Gersten, & Sailor, 1984). Smith (1985) described intensive treatment of severe problem behaviors of autistic adults in community home and work settings in Rhode Island. These and similar efforts need to be extended so that we can offer a high quality of life to all people who experience severely handicapping conditions.

Research and demonstration efforts are needed in the following related areas: organizational variables associated with good living environments, nonaversive treatment of severe problem behaviors, staff development and training technologies and procedures, early screening and treatment of aberrant behavior, effective guardianship and advocay services, early support to families to prevent institutionalization and out-of-home placement, ways to promote and maintain social support to persons residing in group homes, and ways to assess the quality of social interactions and individual affect.

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In Response to Lyle T. Romer

Trends and Issues in Developing Community Living Programs for Young Adults Who Are Deaf-Blind and Profoundly Handicapped

Stephen S. Barrett

Introduction

Lyle Romer's excellent paper on quality assurance in community living programs for those who are multiply handicapped with deafness and blindness explores the apparent strengths and weaknesses of current approaches while proposing a model that deals objectively with what, by nature, must lend itself to subjective measure. Dr. George Singer, in his response, comes to terms with that challenging issue in light of the frequent inability of these people to communicate personalized feelings of satisfaction.

The goals of my contribution are to (a) present trends and issues observed in community living programs for people who are deaf-blind; (b) identify the population of concern and present its definition according to various sources; (c) present a functional description based upon observation; (d) focus upon a continuum of community living alternatives; and (e) consider the role of parents in planning, funding, and implementation of new programs. Several issues which are inherent in increasing the availability of community living options for people who are deaf-blind and profoundly handicapped will be discussed.

Defining the Population

Most efforts to define "deaf-blindness" have been concerned with eligibility for service, while attempting to reflect how the condition affects ability to function in different domains.

The U. S. Department of Education's Office of Special Education Programs (SEP) defines deaf-blind children as those who have "concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational problems that they cannot be accommodated in special education programs solely for deaf or blind children" (Federal Register, 1977, p. 42,479).

Rehabilitation Services Administration (RSA), also administered under the Department of Education, defines a deaf-blind person as one who is considered legally blind under the laws relating to vocational rehabilitation in their state, and "who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification and the combination of the two disabilities causes extreme difficulty for the person to attain independence in activities of daily living, psychosocial adjustment, or in the pursuit of a vocational objective" (Konar & Rice, 1984, p. 14).

In spite of the widely publicized number of children born with deaf-blindness during the rubella epidemic of 1963-65, the incidence of deaf-blindness among children in America has been stable. Statistics provided by State Coordinators for Deaf-Blind Children, working in programs funded under Title VI-C of the Education of the Handicapped Act as amended, and administered on the federal level by Special Education Programs, report a steady incidence of the condition (SEP, 1985).

Statistics presented by age groupings in 1974 (Dantona, 1974) and eleven years later in 1985 (SEP, 1985) are remarkably similar in disputing the notion that we face only the challenge of serving individuals born during the 1963-65 epidemic (See Table 1).

Table 1.

Summary of Deaf-blind Students by Age Grouping
1974, 1985

Age Group	Dantona (1974)	SEP (1985)
0-2	60	149
3-5	415	436
6-11	2241	920
12-17	852	998
18-21	315	1031
Age unknown	408	736
Total	4,414	4,270

Two observations can be made. First, the "bulge" of students in 1974 was clearly in the 0-11 combined age grouping as compared to 12-21 years in 1985, reflecting the "aging out" of the population. Second, the incidence of deaf-blindness among young children ages 0-11 is higher in 1985 (1,505) than it was in 1974 (1,278). The latter is no doubt at least partially attributable to advancements in identification of children with severe handicapping conditions and the growing sophistication of medical treatment which has enhanced the survival rate of these children.

Obviously, demographics such as these give limited information on the characteristics of the population. A seven-year study of the medical characteristics of 141 children diagnosed as deaf-blind, conducted by the Siegel Institute for Communicative Disorders

at Michael Reese Hospital in Chicago, reported high incidences of neurological disorders, orthopedic problems, language and communication disorders, and other medical problems present in addition to vision and hearing impairment (Stein, Palmer, & Weinberg, 1980).

More recent research has focused on the delayed manifestations of the Congential Rubella Syndrome, including diabetes, thyroid disease, ocular damage and other effects (Sever, South, & Shaver, 1985), and the impact upon family dynamics (Appell, 1985).

Population of Concern

The greatest portion of youth born with deaf-blindness during the rubella epidemic of 1963-65 now falls in the age range of 21 to 23 years. As they leave Special Education services which are mandated through age 21 in most states, parents, educators, and posteducation service providers must consider those gains which have been made and what service options are needed to meet the future needs of this population.

Fullest participation in the least restrictive community-based environment, with the individual allowed to make the most of self-help and independent living skills acquired through Special Education programming, is the ideal. Neither custodial care in large institutions nor total dependence upon family members throughout adulthood is a humane or cost effective option.

Even with support services available for those parents who choose to have their children live at home, many parents are not able or willing for this to occur. Having a young adult who is severely handicapped live at home with parents or other family members should always be an option or choice that is available, but it should never become the only alternative to institutionalization.

The author once had the privilege of presenting testimony before the Texas Legislature's Senate Committee on Human Resources in support of Senate Bill 320 which subsequently authorized funds to establish two model Community Living Programs for young adults who are deaf-blind and multihandicapped. A descriptive narrative of the population, based upon many years of direct contact and observation, concluded that

> many of these children . . . have additional handicapping conditions including congenital heart defects, orthopedic problems, cleft palate, and (whether correctly or not) have been diagnosed as being mentally retarded. The children survived, and for the past dozen years, have been served in special education programs designed and funded to meet their needs.
>
> They have been striving to master the most basic of self-help skills, including communication, dressing, feeding and travel. Most of these kids have a long ways to go, and unfortunately, some will never completely master these tasks which the rest of us take for granted. Many will need continued training and supervised living services (Barrett, 1981, p. 5).

While not particularly eloquent, the description is probably still valid today. The primary difference, of course, is that "children" have now become young adults.

Some Hard Questions

In considering the planning and development of Community Living Programs (CLPs) for young adults who are deaf-blind and/or profoundly handicapped, there are several issues of a philosophical nature that must be explored, as direction and focus of plan development are often determined by philosophical values. I refer to these as "hard questions" for obvious reasons and because no two people will necessarily agree on their resolution.

Issue 1. What Constitutes Deinstitutionalization?

Deinstitutionalization of persons with severe handicaps is a topic of great importance, with philosophical, economic, and legalistic ramifications. The term itself can be used to describe the systematic movement of persons with severe handicaps from large, segregated facilities into smaller community-based programs. It can also describe a process which entails the social, economic, and bureaucratic issues pertaining to reallocation of funds from institutional to community settings (Lakin & Bruininks, 1985).

Issue 2. Deinstitutionalization vs. Depopulation

In some states the emphasis is on the latter, with many individuals with severe disabilities being placed in nursing homes or other living arrangements which provide total custodial care. The two concepts must not be confused. One gives hope for movement to a less restrictive community-based environment with an atmosphere conductive to personal growth and community integration; the other gives up virtually all hope.

It is not uncommon these days to hear that a certain state has plans to reduce the size of its institutionalized population from perhaps 2,600 persons to 300 individuals. We should never hesitate to question the quality of life afforded those 300 individuals still institutionalized and to advocate their community placement. Appropriate planning and resources must be applied to make certain that individuals with the severest disabilities, including young adults who are deaf-blind and multiply handicapped, are not overlooked.

Issue 3. Reinstitutionalization

There must be concern for the many youth served under P.L. 94-142 and educated in public school settings who are exiting the school systems in large numbers. Without appropriate planning and development of Community Living Alternatives, many young adults who are deaf-blind are not going to be able to live in the community and will ultimately be placed back in institutional settings.

Issue 4. Personal Value Systems

Do you believe the goal of transition to be a smooth continuum and expansion of services from the arena of education to life in the community, with the individual afforded the opportunity to live as naturally and fully independently as possible? What level of importance should be placed upon the belief system of an agency or individual? People who are deaf-blind or profoundly handicapped and in transition from Special Education to post-education services, their families and advocates, have the right to know the value systems of agencies charged with the responsibility of providing services. These rights are expressed in Table 2 (Barrett, 1986).

Issue 5. Transition as Criteria of Success

Transition to community-based services, including options for employment, leisure, and recreation (all provided in a natural community environment) should not only be the goal of Special Education but also the final criterion of its success. How else can the investment of tens of millions of dollars devoted to special education of children and youth with deaf-blindness be justified?

The Range of Community Living Options

Programs attempting to develop community living services must consider the needs of the individuals to be served, their anticipated needs of supervision in community-based residences, and the range of appropriate models. As pointed out by Dr. Singer in this publication, the population of individuals who are deaf-blind is as diverse and

Table 2

Declaration of Rights of Young Adults with Disabilities in Transition to Community-based Services

The philosophical foundations of transition have several components which set forth its goals and purpose. These include the following:

1. People with disabilities have the right to live in the community, in regular integrated neighborhoods, and have access to all the community has to offer.

2. They have the right to meaningful employment, working with nondisabled co-workers in regular employment, earning fair wages, with whatever support and supervision is necessary for them to become successful.

3. The above services, including opportunities for leisure and recreation, must be provided in natural community environments that encourage interaction with other members of the community.

heterogeneous as any population of individuals with disabilities. No one model or degree of supervision will meet the needs of more than a few individuals.

Table 3 represents a continuum of community living options based upon degree of supervision provided, ranging from heavily supervised to minimal or no supervision (Lessard, 1984). A broad range of options, with narrative description of each is presented in Table 4, ranging from least restrictive to most restrictive (Cotten, in press).

Table 3

A Continuum of Supervised and Semi-independent Living Options in the Community (Lessard, 1984, p.16)

Intermediate Care Facility (ICF-MR)	Heavily Supervised
Community Residence Programs	Moderately Supervised
Staffed Apartments	Live-in Staff Supervisor
Semisupervised Apartment Living	Support Staff Only
Independent Living	No Scheduled Support

Parent Involvement in Planning, Funding, Implementation

In a later section, I will present trends observed while visiting and participating in the development of Community Living Programs (CLPs) for young adults who are deaf-blind. However, one trend is particularly noteworthy and commendable, and that is the high degree of parent involvement in all phases of planning, funding, and implementation of CLPs in five states.

Table 4. Alternative Living Arrangements (ALA)
(Cotten, in press)

1. OWN HOME — This is a place where the person lives as a responsible member of a family, or alone, with at least half of the responsibility for the operation of the home.

2. APARTMENT — This is an apartment where the person lives, again assuming at least half of the responsibility for the operation of the apartment.

3. SHADOW SUPERVISION — This is an ALA where the individual lives in an apartment and receives only minimal supervision and training from a person living within close proximity.

4. SHARE-A-HOME — The individuals are able to care for their own personal needs but, for a variety of reasons, are unable to live alone. This is a complementary arrangement where each member contributes to the overall operation of the homes.

5. SUPERVISED APARTMENT — This is an ALA which enables a person to live in an apartment setting with supervision and habilitative training from individuals living within the same apartment complex.

6. GROUP HOME — This is a home providing supervision and training in a home environment with live-in house parents. Individuals should have basic self-help skills, a means of communication, the ability and motivation to go to a day program, and should demonstrate a level of social skills which is acceptable in the community.

7. PERSONAL CARE HOME — This is an establishment operated and maintained to provide residential accommodations, personal services, and social care to individuals who are not related to the licensee and who, because of impaired capacity for self-care, elect or require protective living accommodations but do not have an illness, injury, or disability for which regular medical care and 24-hour nursing service is required.

8. FOSTER HOME — A foster home is the home of a person or family group not related to the client who cares for one person or more on a free basis.

9. ICF/MENTAL RETARDATION — A facility for mentally retarded persons, established primarily for the diagnosis, treatment, and habilitation of the individual. It provides 24-hour supervised residential living with individualized habilitation services geared to help each resident reach and maintain his maximum functioning capabilities.

10. INTERMEDIATE CARE FACILITY — A health-related institution planned, organized, operated and maintained to provide facilities and services (which are supportive, restorative, and preventive in nature, with related social care), to individuals who, because of a physical or mental condition, or both, require care in an institutional environment but do not have an illness, injury, or disability for which regular medical care and 24-hour nursing services are required.

11. ICF/SNF — A transition from ICF to SNF for those individuals who are becoming medically frail.

12. SKILLED NURSING FACILITY — A health-care institution planned, organized, operated and maintained to provide facilities and health services with related social care to inpatients who require medical care and 24-hour nursing services for illness or disability.

This involvement is perhaps most evident in Texas, New Jersey, Illinois, Florida, and South Carolina, among others. That is to say, the development of CLPs in these states would not have occurred without the leadership and driving force of the parents.

In Texas, members of the parent organization met with service providers to form an Interagency Task Force on Future Services to Deaf-Blind Persons. This has now been in existence for seven years. An initial goal was to formulate a legislative package requesting state authorization and appropriations to conduct statewide identification and needs assessment of Texans, who were deaf-blind, and to establish up to three CLP models across the state.

After considerable effort, primarily on the part of the parents, these services and programs were implemented. Parents played the lead role in reaching out to service providers, contacting local legislators, coordinating advocacy for CLPs and the bills introduced before the legislature. They played major role in implementation and have a continuing role in monitoring quality of service.

The Task Force itself has enjoyed a series of major accomplishments in its short history, including statewide and regional training, support for local interagency efforts, advocacy, public service announcements, service directories, dissemination of information, and the joint development of a Model Transition Plan.

Activities in other states have been no less successful and in each it has been the parents who played the lead role. In New Jersey and Illinois, for example, parents have been extremely successful in working with state and privately funded organizations to secure commitments for initial construction costs, day program alternatives, staff, and other needs. Each has benefited from the support of a strong interagency coalition of parents, family members, and service providers. In Florida and South Carolina, parents have helped launch efforts to plan and implement new community living services based upon interagency cooperation.

In past years, activities such as these developed in isolation with few models being presented and little in the way of technical assistance. However, this is changing rapidly through the efforts of the two SEP-funded Technical Assistance Centers in deaf-blindness, which became operational October 1, 1984.

Newer efforts to establish CLPs, in states such as Florida, South Carolina, and others, don't have to "re-invent the wheel" and can learn from the efforts of others with technical assistance provided by Helen Keller National Center and The Association for Persons with Severe Handicaps (TASH).

At the beginning of our Technical Assistance Center project, we were able to identify thirteen different programs which had established CLPs. We visited many of these programs, met with their staff, and observed a continuum of services ranging from those programs providing minimal assistance and supervision to individuals living in their own apartments to those providing much more intensive support to individuals with multiple medical and self-care needs.

During 1985, our project sponsored three national and bi-regional training workshops on all aspects of developing CLPs, held in Dallas, Washington, and New York. These were attended by representatives of over 100 agencies. Follow-up contact with participants has allowed us to identify ten additional states where agencies are seriously attempting to replicate existing models or to establish new approaches to community living. We are developing intensified technical assistance plans to assist those agencies in their efforts.

Additional Trends in CLPs

Several trends are apparent among those efforts, including the previously mentioned role of parents (see Table 5).

Table 5

Trends Observed in Developing Community Living Programs for Young Adults Who Are Deaf-Blind

1. Parents of youth with deaf-blindness are playing the lead roles in almost all of these states. Well-organized parent associations have approached their state legislatures and state agencies for funding and support. In four particular states, there are new community living programs becoming operational almost exclusively due to the work of parent organizations. This important trend is becoming the rule rather than the exception as all ten states we are currently working with have strong parent involvement.

2. Funding sources other than federal dollars are being tapped. Four states have obtained sponsorship and funding through religious organizations and two states are relying almost 100% on state-appropriated dollars. Another source being utilized is that of real estate syndication.

3. Interagency planning of community living programs is occurring. Typically involved are such programs as Special Education, State V.R., Mental Health, Mental Retardation, Developmental Disabilities, Public Health, local service organizations, parents, and consumer organizations.

The Issue of Categorical vs. Integrated Settings

There can be no doubt that many issues remain in developing community living services for young adults who are deaf-blind. Paramount is the issue of what constitutes an integrated setting and the feasibility of including persons who are deaf-blind within either CLPs established for persons with other handicaps or in full integration with nonhandicapped peers.

The Transition Case Manager hoping to facilitate community-based residential placements for young adults who are deaf-blind and/or profoundly handicapped faces a dilemma. Few CLPs providing minimal supervision to clients feel comfortable serving people who are deaf-blind. On the other hand, programs designed specifically for young adults who are deaf-blind are still relatively scarce and may be years from implementation in many states.

There are indeed individuals educated under the category of "deaf-blind" who possess a greater degree of functional use of vision and hearing than others. These are the fortunate ones whose needs may be adequately met in existing programs.

Program models for persons who are considered mentally retarded lean greatly toward the Semi-Independent Living Program (SILP) model where as little as ten hours of supervision per month is provided (Halpern, Close & Nelson, 1986). Such models have great limitations in providing services to persons who are severely or profoundly handicapped (Lakin & Bruininks, 1985). Thus the dilemma.

Service agencies dveloping CLPs exclusively for people who are deaf-blind may have had little choice due to the reluctance of other agencies to include individuals who are deaf-blind for lack of training, qualified staff, or other considerations. Additionally, the population served is often determined by the funding source of the CLP or service mandates which are categorical in nature.

Staff working in Special Education, Vocational Rehabilitation, programs for the Developmentally Disabled, or other service systems attempting to plan and provide transition services for persons who are deaf-blind frequently encounter such obstacles,

which are chiefly due to lack of training, awareness, and preparation on the part of local community service providers. All these factors may have contributed to the development of CLPs exclusively for individuals who are deaf-blind.

In spite of how one feels about the complicated questions involved, no one model, regardless of the population it is designed for, can meet the needs of all people (Cotten, in press). It is hoped that people who are deaf-blind can be appropriately served in the full range of community living options described by Lessard (1984) and others, with placement based upon need and in the least restrictive setting.

A Concept of "Supported Living"

Individuals responsible for implementing state-of-the-art vocational programs with persons who are severely or profoundly handicapped have noted the associated need for community living options (Kregel, Wehman & Seyfarth, 1985; Halpern, 1985). Going back 12-13 years, it was the author's experience in conducting competitive job placements of adults with deaf-blindness that obtaining the placement was challenging, yet relatively easy, when compared to attempting to assist the individual in locating suitable housing.

Supported employment theory and practice has several basic components in its structure that appear to be applicable to a model of "Supported Living." These include individualized functional assessment of skills, close supervision—a 1:1 or 1:3 staff-to-worker ratio as indicated, a wide range of employment settings and options, and an approach that says that "whatever support this individual needs on the job site to become a productive worker will be provided" (Barrett, 1986, p. 12).

This unique approach to employment needs to be considered in the process of individualized selection of community living options. The key elements, similar to those observed in supported employment programs, would be in (a) functional assessment of skills in realistic living environments, (b) consideration of the use of residual vision and hearing, if any, (c) specialized use of adaptive equipment or techniques when indicated, (d) close supervision and training, and (e) support provided over an indefinite period of time, as necessary.

There might be similarities to the SILP model reported by Halpern, Close, and Nelson (1986) in the case of individuals who may function well with limited supervision. Differences might be in the areas of staff training, specialized communication skills training, identification and funding of support services, and amount of supervision.

This approach would not be feasible for all persons who are deaf-blind or profoundly handicapped, since there must be a recognition that some have had little or no formal training in self-care skills, have been institutionalized for much, if not all, of their lives, and possess many serious behavior patterns of self-abuse aquired through years of neglect and lack of appropriate service.

However, an approach based totally upon individualized assessment of the person's skills and needs, along with supportive training in actual living environments, could focus on helping each individual live in the least restrictive setting possible.

A concept such as "Supported Living" must become a part of the transition planner's repertoire and should be applied to the greatest extent possible in order to assist young adults who are deaf-blind and profoundly handicapped in reaching their fullest potential for community living.

Conclusions

In reviewing the history of residential placements of young adults who are deaf-blind and/or profoundly handicapped, we find that a few options have traditionally been made available. These have been (a) living at home with parents, siblings, or other relatives, (b) institutionalization, or (c) living in the community in a supportive setting with only as much supervision as was necessary. The first alternative is not always available or desirable and, often in the past, has led to the second one, which is neither humane

nor therapeutic. Clearly, it is the third alternative that is caring, humane, cost effective, and achievable.

Organizations hoping to establish community-based living alternatives face tremendous challenges in cost, program design, personnel, and the uncertainty of continued state and federal support. Yet, if transition to community-based services is the goal and final product of Special Education, community living is the key. Parents, service agencies, and advocates must work together to expand the options currently available for community living and to seek new answers to some very hard questions.

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Report of the Working Group on Community-based Housing Options

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Introduction

The group met to develop recommendations to policy makers regarding community residential options for young adults who are deaf-blind. The group agreed on the following philosophical premises:

> All individuals should have access to the benefits of our society including those people who are the most severely handicapped. The concept of zero exclusion which has been applied to school services should also apply to the provision of community residential services. In developing the following recommendations, the committee focused its concern on the population of individuals who experience severe and multiple handicaps of deaf-blindness. While all severely handicapped persons are deserving of high quality community residential services, our focus was on those persons who are graduating from public school services without having developed complex symbolic communication skills and who may have lifelong need for several services, such as physical therapy, occupational therapy, medical support, behavioral programming, along with assistance with

normal activities of daily living. In this context, we did not primarily address the residential needs of those individuals who experience normal intellectual functioning, or those persons with mild to moderate handicaps who possess complex symbolic communication skills and the skills to live in semi-independent settings.

Those individuals, who are profoundly handicapped, who are the focus of our concern, will need intensive lifelong assistance to participate in activities of normal community life. These individuals have, with some rare exceptions, been excluded from community living even in those states which have developed community living options for moderately and severely handicapped individuals. It is our intention to call attention to their needs and to assert that they, too, deserve one of the primary benefits of participation in society—a home. Thus, we assume that all individuals, regardless of the severity of their handicapping conditions, may benefit from small homelike residential living provided that individualized needs for services are fully met.

Public policy is an expression of values; and, as such, we believe that public policy on community-based housing options should reflect the following:

1. Individuals who are deaf-blind should have access to the benefits of our society, including a home in the broadest sense of a place of refuge, individual recognition, and support.
2. Individuals who are deaf-blind should have access to valued daily activities, including work, commerce, and recreation with individuals who are caring, respectful, and who can communicate with them.
3. Individuals who are deaf-blind should have their individual health, communication, and behavioral treatment and training needs met, including the opportunity as adults for continued learning.

Program Characteristics

Programs designed to provide community-based housing options for this population should include the following:

1. Living arrangements that meet the individualized needs of this population including services for communication, mobility, self-care, and physical and mental health needs.
2. Individual case management and advocacy, including individualized needs assessment, service linkage, and monitoring of service delivery. These case management services would make generic community services available.
3. A full array of services to these persons living in natural and foster homes, including transportation, in-home respite, benefits, maintenance, care-giver training, counseling, and adaptive equipment.
4. Quality assurance mechanisms that give a significant voice to parents and related service providers. These mechanisms would prevent abuse and help to maintain valued lifestyles.
5. A system to attract, train, and support high-quality leadership and direct service personnel in the field of residential services.
6. A system and incentives to enlist the personnel development resources of universities, junior colleges, and vocational training programs including innovative programs such as mentorship and apprenticeship.
7. Systems for job advancement and other incentives in order to maintain high quality personnel.

Issues

At present there are severe deficits in public policy and service delivery. These deficits prevail at virtually every level and negatively affect every aspect of the residential service system. In order to ensure quality community-based housing options for those who are profoundly multiply handicapped with deaf-blindness, some of the issues and obstacles which must be addressed include the following:

1. Low public and professional awareness, understanding, and expectations for this population, with a lack of organized advocacy efforts for this low-incidence population.
2. A history of reliance for services for this population on traditional congregate programs that dilute family/community bonds, and the exclusion of this population from new community-based services and programs.
3. A lack of mandated adult services and no single, clearly identified system or agency responsible to provide services.
4. Lack of interagency planning/coordination for services.
5. Lack of commitment to full, long-term funding for quality residential services, and a lack of fiscal commitment to family support services.
6. A lack of alternative incentive mechanisms including communication between business/private industry and social services.
7. The need for a system of adequate compensation and incentives that will attract service personnel who are knowledgeable about sensory deficits and well trained in alternative communication methods and behavior management.
8. A lack of higher education commitment and a lack of federal incentives to prepare service personnel for low-incidence populations, including community service workers, as well as teachers.

Recommendations

1. Individuals who are deaf-blind should be prepared for community living through the following:
   a. Community referenced/intensive school instruction.
   b. Individual Transition Planning (ITP) for students 15 years and over. Each ITP should include, but not be limited to vocational, health, communication, residential, financial, guardianship, and case management concerns.
   c. Training for parents in ways to enhance domestic, community and leisure skills.
2. The development of model demonstration projects for comprehensive family support services should be encouraged and supported.
3. Higher education programs for training leaders in residential services should be created by combining the expertise from teacher training programs with that of other faculties, such as those in business, management, leisure studies, and social work.
4. The technical assistance role of state and multistate centers should be expanded to include training of community service personnel and family members.
5. The use of new technologies to promote staff and family training in community services should be encouraged.
6. Effective dissemination of information about existing quality community services for deaf-blind and other profoundly handicapped individuals should be encouraged and supported.
7. Existing service providers, advocacy, and professional organizations should be informed about the need to serve these and other individuals excluded from community-based options.
8. Information about statewide systems-change efforts from states that have created successful services for these individuals in the community should be disseminated.

9. Planning groups addressing major issues in providing quality services for low incidence populations, e.g., family support services, transition planning, and residential service development, should be convened.
10. The formation of alliances with other advocacy organizations and service providers who serve low-incidence populations should be promoted.